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ABSTRACT

This manual contains training materials on full participation in independent living for a national conference for personnel in agencies concerned with independent living for people with disabilities. Preliminary materials include the conference agenda, background information about the trainers, and organizational information on Independent Living Research Utilization and the National Council on Independent Living. The first section provides an overview of the Research and Training Center on Full Participation in Independent Living, which is currently planning nine research and 13 training projects. One of these projects is described in the following section titled: "Independent Living and the New Paradigm of Disability: Building Knowledge, Consensus, and Action." Next is a paper, "Consumers as Collaborators in Research and Action" (by Glen White and others) that describes a model of participatory action research involving collaboration between researchers and a "consumer empowered team." Next is an overview and brief history of the "citizens' concerns report" method for citizens with disabilities. The following section is a reprint of a paper titled: "The Concerns Report: Involving Consumers in Planning for Rehabilitation and Independent Living Services" (by Stephen Fawcett and others). The manual ends with a community concerns report participation survey. Attached are the teleconference list of participants and evaluation forms. (Some sections contain references.) (DB)

IL NET Presents…

Teleconference:
Full Participation in Independent Living: What Does it Mean?

September 25, 2002

ilnet

Expanding the Power of the Independent Living Movement

IL NET
an ILRU/NCIL National Training and Technical Assistance Project

Expanding the Power of the Independent Living Movement

FULL PARTICIPATION IN INDEPENDENT LIVING: WHAT DOES IT MEAN?

A National Teleconference

Participant's Manual

September 25, 2002

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Full Participant in Independent Living: What does it mean?

A National Teleconference

Participant's Manual

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FULL PARTICIPATION IN INDEPENDENT LIVING: WHAT DOES IT MEAN?

A National Teleconference
September 25, 2002

AGENDA

Welcome and Introductions

History Behind and Rationale for the Community Concerns Report Method Survey

The CCRM Survey Development Process

How This Process Contributes to a More Relevant Outcome

Q & A

What the Preliminary Results Tell Us About Full Participation in the Community

Key Concerns that People with Disabilities have Identified as Barriers to Community Participation

Feedback from Teleconference Participants on Personal Experiences, or Those of Consumers, with Full Participation in Community Life

Q & A

How Teleconference Participants Can Help with Possible Solutions Identified in the Survey

Q & A

Wrap-up

ABOUT THE TRAINERS

Dot Nary is Training Director at the Research and Training Center on Independent Living at the University of Kansas, as well as a doctoral student in the Department of Human Development and Family Life at KU. She worked as a peer counselor and program coordinator at several Centers for Independent Living in upstate New York and currently serves as president of the board at Independence, Inc. in Lawrence, Kansas.

Glen W. White, Ph.D., has been involved in the rehabilitation and independent living field for over 30 years. He is currently Director of the Research and Training Center on Independent Living at the University of Kansas. He serves as Principal Investigator of the recently funded Research and Training Center on Full Participation in Independent Living. Dr. White has had numerous opportunities to work with consumers with disabilities in identifying, developing and shaping on-going disability research. He has conducted research in the areas of housing, advocacy, developing community support for independent living centers, and for the past several years he has been developing a systematic line of research in the area of prevention of secondary conditions. He is past president of the National Association of Rehabilitation Research and Training Centers, Chair- elect of the American Public Health Association's Disability Forum, and serves as an advisor and consultant to many national organizations.

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ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL's efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation's capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.

ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.

- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.

- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.

Research and Training Center on Full Participation in Independent Living

OVERVIEW

www.rtcfpil.org

Research and Training Center on Full Participation in Independent Living

ABSTRACT

The Mission of the Rehabilitation and Training Center on Full Participation in Independent Living (RTCFPIL) is to enable and empower persons with disabilities from diverse cultures, varying socioeconomic strata, and emerging disability populations to more fully participate in society through research, training, and dissemination of person-environment strategies that encourage full participation in society.

This mission is based on independent living philosophy and values. The IL values were used to establish the mission and will be used to guide the RTCFPIL. We believe that:

- Society is enhanced by the leadership of people with disabilities, because of their first-hand experience and expertise with disability issues.
- Consumers as collaborators enrich all aspects of research, training, and dissemination activities.
- Consumer's decision-making should extend beyond personal decisions to involvement and decision-making for the design, operation, and evaluation of services so that consumers from diverse cultures and emerging disability populations can fully participate in society.
- Consumers with disabilities should be served (regardless of disability type or severity) through progressive options and policies that provide inclusive, accessible, high-quality, community-based services that reduce their dependency and increase their full participation in independent living.
- Developing accommodations for people with disabilities from diverse cultures and from emerging disability populations requires optimal environmental supports and strategies (e.g., making environments accessible, providing services, or developing accommodations) to enhance consumers' choices to ensure full participation and quality of life.

The RRTC mission will be implemented through multiple research and training activities. These activities will be influenced by independent living philosophy and values. Further, the researchers will emphasize participatory action research, in which consumers take an active role throughout the research process.

The Analytical Research Framework will provide the master plan for conducting disability research and training activities both for the proposed RRTC and for others in the field of disability research. Specifically, the proposed RRTC on Full Participation in Independent Living will develop, test, and use measurement tools to investigate the interactional relationship between person and environmental factors and their effects on

full participation in independent living by people with disabilities, including those from diverse cultures and from emerging disability populations.

Based on the Analytical Research Framework, there will be four core areas of intervention development and testing. These core areas include: 1) increasing the knowledge base about the emerging universe of disability, 2) community participation and wellness, 3) cultural IL accommodations, and 4) personal and systems advocacy.

Presently, there are nine research and 13 training projects planned for this proposed RTC. We will add new projects as old projects are completed. Input for all RTC activities will be received from on-going advisement from the RTC's National Advisory Board, disability advocates, and our consumer-empowered teams, who will provide continuous shaping and revisions of research and training activities throughout the five year cycle of this research grant.

The RTC staff is committed to conducting research activities that are both scientifically rigorous and relevant to the lives of people with disabilities.

Independent Living and the New Paradigm of Disability: Building Knowledge, Consensus, and Action

A Research and Training Project of
The Research & Training Center on Independent Living
The University of Kansas
Lawrence, Kansas
www.lsi.ukans.edu/rtcil

Research Project One R-1

Name: Independent Living and the New Paradigm of Disability: Building Knowledge, Consensus, and Action

Principal Investigator and key staff:

Name and Degree	Position	% time
Glen W. White, Ph.D.	Director, P.I.	30%
James F. Budde, Ed. D.	Co- Director	10%
Dorothy Nary, M.A.	Training Director	10%
David Wyatt, M.A.	Graduate Research Asst.	15%
Vivian Chapman, B.A.	Graduate Research Asst.	25%

Length of Project: 18 months

Statement of the Problem: The NIDRR Long Range Plan 2000-2003 (NIDRR, 1999) identifies many disability issues that affect the contextual landscape of independent living. Chief among these are the increased emphasis on person-environment factors (pp. 68578, 68584), emerging new populations in the universe of disability (e.g., multiple chemical sensitivity syndrome, chronic fatigue syndrome) (p. 68595), and needed cultural accommodations for populations (e.g., Native American, Hispanic American, African American) (p. 68601) who have not traditionally benefited from IL.

There remains a tension concerning the definition of independent living and the new paradigm. There are some in the independent living community who rightly ask, "Isn't the new paradigm the same as the old paradigm?" Or, "What's wrong with the traditional paradigm that has been described by DeJong (1979) and later refined by the National Council on Independent Living?"

This research will engage independent living experts and consumers of independent living services to address these questions and provide a strong foundation for future disability research.

Brief Summary of Project: To gain a strong consumer influence for this five-year RTC on Full Participation in Independent Living, this project will entail two specific phases. First, it will conduct a Consumer Concerns Report to help establish a five-year research agenda which will help shape proposed projects for this grant competition and provide direction to the RTC for future projects to be addressed in later years. Second, in the middle of year two the project will organize a national consensus conference, which will allow discussion of the Consumer Concerns Report, identifying concerns and potential solutions that the Center can work toward implementing during years two through five. Each phase is discussed below.

It is often the case that those individuals who stand to gain the most from research are the last to benefit. Researchers often become so narrow in their focus for the sake of experimentation that consumers for whom the research was originally designed to help, are left out of the process. To remedy this, the Consumer Concerns Report Method (CCRM) (Schriner & Fawcett, 1988) was designed to serve as an agenda-setting tool. According to the CCRM, the survey is developed under the guidance of the population of interest. A core group of individuals are selected from a population of their peers who are experiencing similar concerns. This group will help develop a survey that is representative of their concerns, and the concerns of their peers. The survey will contain two questions for each item, one inquiring about the importance of the concern, and the other about the participant's satisfaction that the concern is being addressed. The survey is then broadly disseminated using a canvassing approach using traditional organizations (e.g., CIL staff, SILCs, DBTACS) and non-traditional approaches (e.g., low-income health care clinics, and the faith community). The resulting data are then statistically described and shared with those likely to be experiencing the problem. At that time, the group is asked to generate ideas as to how best to approach the outlined problem areas.

This method of data gathering has been used successfully in the past with a variety of groups. One of the first attempts at problem solving through the use of CCRM was by a neighborhood improvement association (Schriner & Fawcett, 1988). Since then, the CCRM has been used by researchers interested in building consumer-generated research agendas, including individuals with mental retardation (Youngbauer & Budde, 1994), individuals with traumatic brain injury (Youngbauer, Williams, & Mathews, 1994), individuals with psychiatric disabilities (Snyder, Temple, Youngbauer, O'Neil, & Cromwell, 1995), and to identify the disability concerns of Perúvians (White et al., in preparation) and Ecuadorians (Chapman et al., in preparation).

The information resulting from the CCRM can be used to guide researchers towards research activities (in addition to those promised to NIDRR) which may be most beneficial to relevant IL and consumer constituencies. The method follows the tradition of empowerment through its focus on the control held by individuals, rather than "experts," such as policy makers or researchers (Schriner & Fawcett, 1988). The CCRM process is consistent with NIDRR's participatory action research emphasis (NIDRR, 1999) (p. 68581).

Research Goal: To actively engage consumers and other relevant constituents in helping researchers review: the definition of IL; the contextual framework of disability and accessible communities; the changing universe of disability; and ways to facilitate consumer collaboration on the conceptualization and execution of research.

Research Objectives:

1. Develop a Consumer Concerns Report Method Survey.
    - Identify a minimum of 10-12 consumers and advocate leaders who are key informants and representative CIL consumers, and those from emerging disabilities and unrepresented disability populations.
    - Charge the key informants identified above to develop a 30 to 40-question survey concerning personal and environmental barriers that affect full participation in independent living and community life for people with emerging disabilities and people with disabilities from diverse cultures. Once items are identified, refine them for the importance and satisfaction ratings format used in the survey. Determine whether different variations of the survey are needed to reach various audiences.
    - Pilot test the survey with 20 consumers to see if the instrument is understandable and produces a representative variability in the responses. Revise the survey as needed.
    - Widely distribute the survey to CILs in cooperation with the National Council on Independent Living (NCIL) and with the Association of Programs for Rural Independent Living (APRIL) national offices. To ensure that surveys are mailed as broadly as possible, utilize mailing lists from the Research and Training Center on Independent Living (RTC/IL) and other cooperating organizations. In addition to sending surveys to CILs, they will also be sent to each of the Statewide Independent Living Councils (SILCs) to determine their concerns and issues with respect to the key issues. Other target populations will be identified by the key informants and the survey preparation team.

2. Analyze the Consumer Concerns Report Method Survey.
    - Enter survey data into an SPSS database as survey responses are returned to the project.
    - Analyze data according to importance and satisfaction ratings.
    - Identify consumers' responses of key person and environment concerns, needs, and strengths.
    - Identify consumer-reputed barriers that prevent people with disabilities from fully participating in society.
    - Complete the CCRM data report from the surveys and make copies of the report for distribution.

3. Conduct a Consensus Conference with invited relevant constituencies to discuss the results of the CCRM and other relevant streams of information.
    - Review the CCRM report findings with all participants through a National Consensus Conference.
    - Note potential consumer-identified solutions to the person and environment concerns that limit full participation in independent living.
    - Identify potential RTC projects that could be implemented to remedy the CCRM survey concerns.

- Include these potential solutions in the overall report.
- In addition to the CCRM data, conference attendees will also listen to Dr. Bonnie O'Day, who will present results from R-2, LaDonna Fowler, who will present results from R-9, and other key informants who will present information relevant to reviewing the definition of IL, discussing the changing universe of disability, and discussing how IL can help people with disabilities not traditionally served by CILs to become more independent in their cultures, communities, and society in general.

4. Inform, dialogue, and coordinate CCRM results with NIDRR grantees and other organizations.
    - Work with NIDRR grantees, including but not limited to: RRTC on Disability Statistics, RRTC on Persons with Disabilities from Minority Backgrounds, Centers for Independent Living, Statewide Independent Living Councils, Center on Emergent Disability, National Center for the Dissemination of Disability Research, and the RSA training and technical assistance provider under Part C of Title VII of the Rehabilitation Act, Model SCI Centers, and others as appropriate.

5. Use CCRM results to inform other RTC/FPIL project activities.
    - Use the findings of the CCRM and the Consensus Conference to guide all internal research, training, technical assistance, and dissemination activities.

Research Hypothesis: A definition of independent living will be understood that influences the contextual framework of disability and accessible community; the changing universe of disability; and consumer collaboration on the conceptualization and execution of research.

Study Design: This project will use the Consumer Concerns Report Methodology (CCRM), which has been used in over 20 states in the U. S. and two international countries with well over 20,000 participants during the past 16 years. The CCRM has been widely used as an agenda-setting tool. This social technology, developed in the early 1980's, places strong emphasis on consumer input throughout the whole CCRM process.

Sample Population: The CCRM surveys will be broadcast to a broad cross section of independent living and non-traditional audiences as described earlier. We anticipate distribution of about 3,500 surveys, and based on past experience, we anticipate approximately a 45-50% response rate. [Note: R-9 will apply the CCRM to American Indian Tribes].

Measurement Techniques: The Consumer Concerns Report Survey uses Likert scale importance and satisfaction ratings as the basis for preliminary needs measurement.

Date Analysis: A computerized scoring program will be used to aggregate analyze survey data. The system uses scores derived from the rating scales and divides the survey items into two main categories of interest: 1) high importance and low satisfaction; 2) high importance and high satisfaction. The analysis of these data will be presented to Consensus Conference attendees. Conference participants' primary task will be analyzing and suggesting solutions for items that are highly important, but for which there is low satisfaction. Likert scoring will be statistically analyzed to prioritize important factors, comparing individual scores against perceived neutrality (within item), and against other scores (between item) using t-tests or Analysis of Variance techniques.

Policy Implications: The information gained from this research project will benefit consumers, CILs, and SILCs, and other coordinating NIDRR agencies by providing a state-of-the-art understanding of independent living and how it relates to person and environment interactions, which affect levels of participation in the workplace, schools, and the community in general. The consumer-oriented nature of this proposed research project allows maximum input on RTC activities from a participatory action research viewpoint (Whyte, 1991; White et al., in press).

Data from the CCRM and the Consensus Conference will be packaged into a monograph which will be distributed to policymakers, funding agents, disability leaders, and other disability researchers to help inform and to serve as a guide for action to stimulate changes in programs, practices, and policies which would allow increased participation for all people with disabilities.

Consumers as Collaborators in Research and Action

By

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Abstract

This paper discusses the role of consumers as collaborators in disability research conducted in the community. A comprehensive model of participatory action research is described and illustrated with research and training projects conducted in a collaborative arrangement between researchers and a Consumer Empowered Team. The paper describes how adherence to the model could be conducted in actual research and training settings and produce outcomes valued by the consumers to whom the interventions were targeted. The advantages and caveats to using the consumer as collaborator approach are discussed.

Consumers as Collaborators in Research and Action

> *"Great discoveries and improvements invariably involve the cooperation of many minds. I may be given credit for having blazed the trail but when I look at the subsequent developments I feel the credit is due to others rather than to myself."*
>
> --Alexander Graham Bell--

Participatory Action Research, what is it? Whyte (1991) states that "PAR is applied research," but unlike traditional applied research, participatory action research (PAR) encourages people in the organization or community under study to actively participate with the research scientist throughout the entire research process--from beginning to end (p. 20). One of the identifying features of PAR is that it empowers participants who are likely to be the targets of the research to have a partnership in shaping the research process (Yeich and Levine, 1992). Santelli, Singer, DiVenere, Ginsberg, and Powers (1998) posit that the action research approach elevates participants to a co-researcher role based on their insider status and local knowledge. This suggests that participants, whether workers in a factory or people with disabilities in the community are valued as experts based on their past history and experiences with the research issue or problem that is being addressed.

Thus, the researcher takes the role of learner to understand better participants' experiences. Some researchers view such collaboration as inefficient and costly, while others invite and use PAR to develop more relevant and rigorous research outcomes. Turnbull, Friesen, and Ramirez (1998) describe the process of involving families with children with disabilities as stakeholders throughout the whole research process. Other researchers support the assertion that PAR enhances the quality of the research process, including problem and hypothesis formulation (Greenwood, Whyte, & Harkavy, 1993), assistance with participant recruitment, and direction for data analyses on identified factors (Santelli et al., 1998).

PAR has been used by researchers in numerous areas including cooperative living (Whyte, Greenwood, & Lazes, 1989), community health initiatives (Fawcett, Paine-Andrews, et al., 1996; Schwab, 1997), cultural research (Chataway, 1997; Lykes, 1997), and self-help groups (Chesler, 1991). In addition, PAR has been used to understand better various disability populations such as persons with psychiatric disabilities (Rogers & Palmer-Erbs, 1994), families with children with disabilities (Turnbull et al., 1998; Santelli et al., 1998), persons with developmental disabilities (Gilner & Sample, 1993), and adults with physical disabilities (White, Nary, & Gutierrez, 1997).

There is a growing literature on PAR (Bartunek, 1993; Heller, 1993; Whyte, 1991), its basic principles (Fawcett, 1991; McTaggart, 1991), and how it can be implemented (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Stringer, 1996).

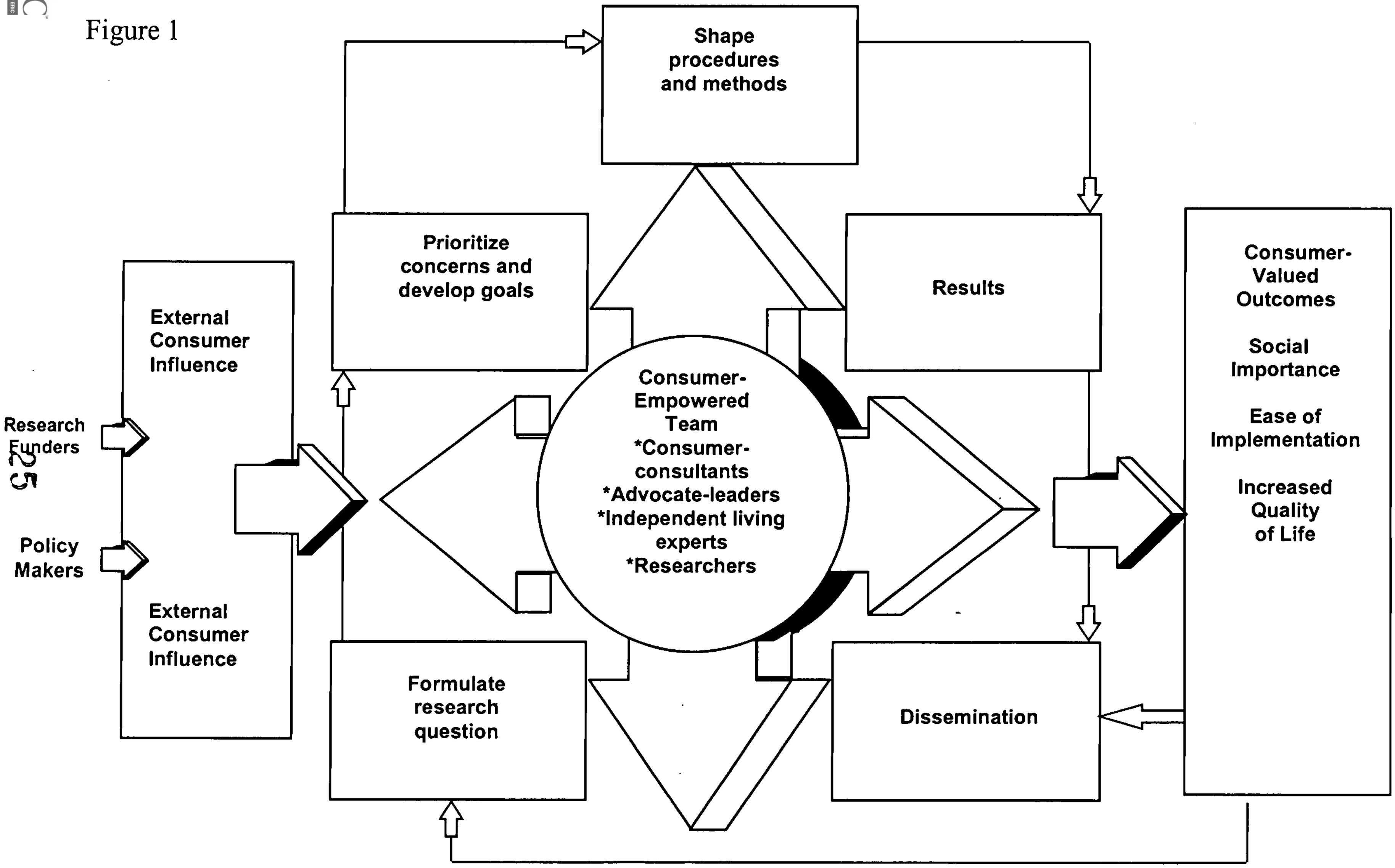
This paper presents and discusses a model for participatory action research as well as examines two case illustrations in which participants with various disabling conditions were invited to be involved in research studies conducted by researchers at the Research and Training Center on Independent Living (RTC/IL) at the University of Kansas.

While the described model is applied to people with disabilities in this case, its application could be used with almost any type of community group.

A Model for Participatory Action Research

Figure 1 presents an illustrative model, which identifies the pervasiveness of PAR throughout the research process. The research process is influenced by both external and internal consumer involvement. Specifically, this PAR model is comprised of four main components: 1) external consumer influences, 2) internal consumer influences through the Consumer Empowered Team, 3) the research process, and 4) consumer-valued outcomes. Each of these components is presented in more detail below.

Figure 1


Shape procedures and methods
Prioritize concerns and develop goals
Results
External Consumer Influence
Research Funders
Policy Makers
External Consumer Influence
Consumer-Empowered Team
*Consumer-consultants
*Advocate-leaders
*Independent living experts
*Researchers
Consumer-Valued Outcomes
Social Importance
Ease of Implementation
Increased Quality of Life
Formulate research question
Dissemination

External Consumer Influence

The influence of consumers' needs is often substantial even before researchers begin a particular research project. There has been a growing trend among policy makers and research funders, such as the National Institute on Disability and Rehabilitation Research (NIDRR) to develop PAR-oriented research priorities.

Policy makers.

Policy makers are often petitioned by special interest groups and individual citizens regarding hundreds of issues. The issues often represent ideas that may not even be on the policy maker's "radar screen." One consumer activist group, ADAPT (American Disabled for Attendant Programs Today) has used tactics to make their calls for change in public policy widely publicized. ADAPT's campaign for accessible public transit began in Denver in 1983 and spawned seven years of demonstrations in cities across the US. At those demonstrations wheelchair users blocked buses by chaining their wheelchairs to them. As a result, ADAPT was in a position to influence stringent requirements regarding public transit in the legislation of the Americans With Disabilities Act 1990. Similarly, AIDS activist groups such as ACTUP (AIDS Coalition to Unleash Power) and TAG (Treatment Action Group) have been so successful at educating themselves and influencing governmental policy using confrontational methods that they now have representation on many government advisory panels. Due largely to their efforts, 10% of the 1992 National Institutes of Health (NIH) budget of $8.9 billion was devoted to AIDS research ("Their Lives," 1993).

Research funders.

Funding agencies often solicit input when establishing research initiatives. Frequently the feedback generated comes from professionals who wish to conduct research in the area. NIDRR is one such funding agency, which has initiated a system for assuring that this input comes not only from professionals, but also from consumers. Their consumer involvement approach is comprised of three components. First, they invite knowledgeable consumers, advocates, and family members of persons with disabilities to help identify real-world problems that need to be addressed through research. Second, in The Federal Register, they release "calls for public comment" on research priorities that they will incorporate in future grant competitions. Public feedback on these proposed research priorities is solicited from various stakeholders such as disability advocates, families of children with disabilities, service providers, and researchers in the disability field. Third, NIDRR frequently involves people with disabilities and those from minority cultures on its peer review panels for various grant competitions. While this process has some critics, it allows consumers to review the specified goals, procedures, and anticipated outcomes of proposed research projects. Consumers' comments provide a reality-check for the relevance of the proposed research, while the scientists on the panels provide input on the rigor and robustness of the proposed research.

Consumer Empowered Team

The Consumer Empowered Team (White, 1995), hereafter referred to as “the team,” consists of consumer-consultants, advocate leaders, project independent living experts and researchers. The composition and design of the team is intended to produce project outcomes that are synergistic and mutually beneficial for participants and researchers. The team is more proximal to research activities compared to the usual consumer advisory board structure. Typically, advisory boards offer consultation at the start of a project and are then presented results after the project is finished.

The purpose of the team is to solicit consumer input throughout the research process. The team composition varies depending upon each project's aims and goals. Team members may be recruited locally, regionally and nationally. Consultations may range from interviewing key informants regarding policy issues or problems to developing contracts with subject matter experts to assist in producing specific research or training materials. The team is not a “one size fits all” approach. Rather, each project assembles its own team based on the particular project needs, goals, and intended outcomes. The Rehabilitation Research and Training Center on Independent Living, reimburses team members for their time and expenses as would be done with any other group of experts.

Team members' perspectives help identify critical considerations of the proposed research. For example, team members frame the research issue from a consumer viewpoint, identify possible root causes of why the problem occurs, under what conditions, and with what consequences. Fawcett (1991) suggests this PAR process enhances the quality of the research process through assessing the social significance of the research *goals*; the appropriateness of the research *procedures*; and the social importance of the *effects* of the intervention. Next, we will review the five boxes outside the CET circle which describe the PAR enhanced research process.

The Research Process

The entire research process starts with formulating the research question (see Figure 1). To answer this question the research goals and issues are developed as well as the procedures and methods identified to produce evidence to answer the research question. The generated data are then analyzed to identify the results and outcomes. Finally, the study results and intervention package, if applicable, are disseminated to targeted audiences. Each of these research elements and how they are influenced through this iterative participatory research process of the team are discussed in more detail below.

Formulate research question.

The team reviews and helps shape the research question within the priorities identified by the funding agency. This participation helps ensure that the research will be more relevant to its intended targets. The iterative nature of the research process naturally generates new research questions from the original research question.

Prioritize concerns and develop goals.

The research question provides direction for the research, but consumers' disability concerns must be prioritized and the goals developed to address those concerns. The team shapes the relevance of the concerns and goals based on their personal experience by framing the particular problem being addressed in the research question. To provide general direction for our research issues and goals, the RTC/IL developed a Consumer Concerns Report Method (Schriner & Fawcett, 1988) which has been used to gather specific information on disability concerns information from people with physical disabilities (Suarez de Balcazar, Bradford, & Fawcett, 1988).

Shape procedures and methods.

Researchers adopt specific approaches to addressing research questions or problems. While the procedures used may embody rigorous methodology, sometimes they may be contrived and unlikely to maintain the desired behavior or outcomes once the research is completed. As researchers, we desire to develop research interventions and outcomes, which can survive in the natural community setting over time. The team teaches us valuable lessons about the delicate balance between research rigor and relevance. Rigorous research may be helpful in building science, but rigorous research that is not relevant to those to whom it is directed is unlikely to be adopted (Rogers & Palmer-Erbs, 1994; Turnbull et al., 1998).

Results.

Traditional research results describe the effects of independent variables on targeted dependent variables and this evidence contributes to existing scientific knowledge. The main emphasis is whether the results have statistical significance, indicate strong correlation effects, or demonstrate a functional relationship between the independent and dependent variables. In a PAR-driven approach, the team can augment the scientific interpretation of the results by challenging researchers to examine the practical meaning and impact the results can have for whom the intervention has been targeted. This is important because consumer-collaborators will have little enthusiasm for research results that produce significant statistical effects, but have virtually no real-life application. Greenwood, Whyte, and Harkavy (1993) state that participant involvement in the research process is "capable of producing both scientifically and socially meaningful research results" (p. 180).

Dissemination.

Consumer collaboration in the dissemination process can shape the products that flow from the research as well as the best formats (e.g., audiotape, Braille, large print, www, etc.) to promote maximum use by intended users. Consumer collaborators who are partners in the research process can be valuable champions in approaching new target audiences for the particular intervention or resulting research products.

Consumer-Valued Outcomes

Consumers can also provide realistic input regarding research interventions and products through their perspective of the social importance of the outcomes, the ease of implementation, and whether outcomes improve some aspect of the consumers' quality of life. Each of these values is briefly discussed.

Social importance.

Wolf (1978) and Fawcett (1991) have described the importance of consumer validation or social validation of research goals and procedures. These authors further suggest that consumer input is also relevant in determining the social importance of the effects of the research intervention and how relevant it is to their lives.

Ease of implementation.

Consumers can provide a perspective that researchers, who are "on the outside" do not have about developing interventions that can be easily implemented by consumers. After the research phase has been conducted, emphasis should be placed on technology transfer from the researcher to the consumer, as recommended in the Institute on Medicine Report, Enabling America (Brandt & Pope, 1997).

Quality of Life.

Quality of life is an important issue to consumers when evaluating research interventions and proposed products. The following example highlights the significance of this issue. A rehabilitation researcher could develop a device to help a person with quadriplegia dress independently, however the energy and time expended to dress may leave the quadriplegic physically exhausted for the rest of the day. While the device was effective in assisting the person with quadriplegia get dressed, the energy exerted to use the intervention outweighed the benefits of dressing independently. Consumers' input is needed throughout the research process to increase the likelihood that research outcomes enhance consumers' quality of life.

It should be noted that the Consumer-Valued Outcomes box has an arrow that returns back to the formulation of new research questions. Ideally, the feedback from

Consumer-Valued Outcomes could inform almost any level of the research cycle, thus creating an iterative process and program of research.

The next section describes two case illustrations in which participants with various disabling conditions were invited to be involved with projects conducted by RTC/IL researchers at the University of Kansas. To demonstrate the flexibility of the PAR process, we will describe both a research study, and a training package, developed in collaboration with consumers. The first illustration is on the development and empirical testing of an advocacy letter-writing package, The Action Letter Portfolio (White, Thomson, & Nary, 1999). The second is the development of resource booklets for people with spinal cord injuries on how to prevent or reduce the incidence of specific secondary complications. Each project is presented from the perspective of the PAR model we have described.

Action Letter Portfolio

During the last thirty years, the US has passed many laws to establish and protect the rights of citizens with disabilities. The most far-reaching legislation is the landmark civil rights law, the Americans With Disabilities Act of 1990 (ADA) (P.L. 101-336), which protects the rights of over 54 million citizens with disabilities (McNeil, 1997) in the areas of employment, public and private accommodations, and telecommunications. Despite passage of the ADA and other disability legislation, however, people with disabilities frequently struggle with discrimination and unfair treatment. One major reason is that fiscal and human resources for enforcing the regulations are limited. Therefore, it is important for citizens with disabilities to learn about the laws that protect them and to gain advocacy skills to promote compliance with these laws.

One social technology developed to meet this need is the Action Letter Portfolio, a self-administered training tool developed to help people with disabilities improve their advocacy letter writing skills. The Action Letter Portfolio outlines the components and methods of writing an action (or advocacy) letter, and provides examples and opportunities for manual users to practice these skills as they learn them. Users can also compare their letters with exemplars included in the manual. Both content (i.e. introduction to the problem, stating a rationale, providing evidence) and form (i.e. inside address, salutation, closing) are taught as essential elements of an effective advocacy letter. The manual provides information on targeting the letter to the proper recipient and on following up with recipients after letters are written. It also contains a section summarizing specific disability laws which can be cited in the letters as supporting information and evidence.

The development of this research project is described using the PAR model. The idea for the manual was conceived by a researcher with a disability as a result of personal frustration in trying to write a letter to an insurance company to advocate for a more durable and lightweight wheelchair than their guidelines allowed. This person wondered why there was no existing manual on how to write effective advocacy letters.

Team Composition

The team consisted of two nationally recognized disability advocates, one person with a severe physical disability, three researchers (two of whom had a disability), and a focus group of consumers who received the Action Letter materials as they were developed. Team members were chosen based on their ability and willingness to participate on this project.

Formulate of the Research Question

To answer this question the team conducted a literature search for exemplar materials. While training materials on letter writing to editors and public officials were found (Seekins, Fawcett & Mathews, 1987), these items were fairly basic and lacked examples of letters that addressed problems typically experienced by people with disabilities.

To learn more about what disability advocates and independent living experts were already doing in this area, the team sent a brief questionnaire to each center for independent living. Respondents were asked to identify the types of advocacy they presently used. Twenty-six percent of those independent living centers or programs responding to the questionnaire indicated that writing advocacy letters was their most frequent method used for advocacy.

Prioritize Concerns and Develop Goals

The survey also requested respondents to identify specific issue areas where advocacy training should be developed. Experts identified 14 different topics as critical for advocacy efforts. These topics included: (a) employment, (b) accessible parking, (c) disability policy, (d) public access, (e) transportation, (f) housing, (g) special services, (h) health care, (I) education, (j) insurance issues, (k) telecommunications, (l) media portrayal of people with disabilities, (m) vocational rehabilitation services, and (n) personal assistance services. These topics provided the team direction in obtaining specific US laws and regulations related to the selected areas (e.g., housing, and the Fair Housing Amendments Act of 1988). Summaries and key points of these laws were then included in the reference section of the Action Letter Portfolio materials.

Shape Procedures and Methods

The team met and discussed personal approaches to advocate for personal disability concerns they experienced, and also reviewed the literature on different advocacy approaches. After much deliberation the team decided that teaching advocacy letter writing skills to consumers was the best course for this project. There were several reasons why this approach was taken. First, letter writing was already being used by centers for independent living. Second, the training could be self-administered, and third, letters provide a permanent product of the consumer's interaction with the intended target of the letter. After this decision was made, the team made a nationwide request to centers on independent living, independent living programs, and consumer-consultants with disabilities to submit exemplary advocacy letters they had previously written. These letters were assigned to one of the 14 identified topic areas based on their content. Team members reviewed them to determine if they had face validity and were likely to produce change.

Communication with consumer focus group members indicated that teaching people how to write effective advocacy letters was a good idea. Consumers recognized that the advocacy letters would leave a "paper trail" as evidence for later actions concerning trends towards non-compliance or continued discrimination. Based on the above information team members wrote a five-chapter manual to serve as a reference guide for writing action letters.

A draft of the manual was sent out for review to identified independent living experts and IL advocacy staff members who were representative of those most likely to use the materials. Following the manual revisions, a study was conducted with participants recruited from a rural independent living center to investigate whether the manual could be used in a self-administered manner to teach the letter writing skills (White, Thomson, & Nary, 1997). This phase incorporated consumer feedback by encouraging participants to record directly in their manuals any questions, ideas for improvement, or suggestions for the next revision of the manual.

Results

This multiple baseline across participants study showed that ALP had modest effects with three of the four participants, indicating that individuals with no experience in writing advocacy letters can acquire these skills through use of a self-administered manual. While these participants increased the number of required elements in their letters, an error analysis indicated that participants frequently showed more improvement in the mechanical elements of the letters (e.g., date, opening salutation, and inside address) than in the content elements of the body of the letter (e.g., explanation of the personal disability concern, and rationale why it is a concern). These results taught the team that mastering the "content" sections of an advocacy letter may require more practice than the mechanical elements.

In a second study, three of the five participants showed moderate improvement in their advocacy letter-writing skills. While members of this group appeared to have difficulty generating personal disability concerns, once they did so, the letters based on these concerns scored higher than those based on hypothetical situations provided by researchers. This suggests that participants are more likely to be invested in writing an advocacy letter under more natural conditions when there is a personal disability concern.

Dissemination

Team members collaborated with other center for independent living staff members to do a national presentation of The Action Letter Portfolio as one tool, which can be used as part of an overall advocacy strategy. The team discussed appropriate dissemination strategies, in order to reach the largest number of consumers. The annual national independent living conference was suggested as an ideal mechanism to disseminate the ALP since several hundred disability advocates usually attend. Information on the ALP will also be disseminated in a product catalog and web page specifically targeted toward disability organizations.

There is strong evidence that there is interest in the ALP as a standing reference tool. Based on our original survey to centers for independent living that asked potential respondents, "Would your center purchase an advocacy letter training manual if one were available? The great majority of responses (86.4%) said they would purchase an advocacy letter-writing manual.

Consumer-Valued Outcomes

In order to prompt consumer feedback about ALP's social importance, ease of implementation, and effect on the consumer's quality of life, each ALP manual includes an evaluation feedback form so that users can provide input regarding revisions for future editions. This information will also help shape new research questions in the area of enhancing consumer advocacy skills and approaches. Given the strong emphasis on advocacy in centers for independent living (DeJong & Lifchez, 1983; Pope & Tarlov, 1991; White, Seekins, & Gutierrez, 1996), we believe that this tool for social and community change will be well accepted by its intended users.

Social importance.

Advocacy is one of the key components of consumer-run centers for independent living. Most centers have advocacy as one of their "core" services for consumers. Sixty-two percent of the centers responding to the survey reported having an advocacy group. . However, the survey responders indicated that less than one-third of the consumers they work with has effective advocacy skills. This suggests that a training manual, such as ALP, might be of high importance for consumers to refer to and use when advocating for a personal disability concern.

Ease of implementation.

This self-administered format allows centers for independent living staff the choice of conducting formal training or encouraging consumers to self-learn the materials. In addition, as designed, the ALP can also serve as a reference manual that staff and consumers alike can use whenever they need to write advocacy letters.

Quality of life.

Consumers have used the ALP to successfully advocate for change at the individual level and at the systems level. One notable example was a series of letters written to an international airport administration about the non-compliance of restroom facilities with current Americans With Disabilities Act Accessibility Guidelines. Following the instructions and examples outlined in the ALP, the consumer wrote advocacy letters to eventually convince the airport administration to spend over $900,000 renovating each of its restrooms to exceed current federal accessibility requirements. Removing barriers to bathroom access is one important example of how using the ALP can increase consumers' overall quality of life.

To further illustrate the flexibility of the PAR process, we would now like to turn to a training project designed to help people with disabilities to prevent or manage secondary health conditions.

Developing Resources for Preventing and Managing Secondary Conditions

People with disabilities are often at risk for other disabling problems. Pope and Tarlov (1991) call these problems secondary conditions, and define them as health problems that are "causally related to a primary disabling condition" (p. 214). Health problems that are considered secondary conditions include, but are not limited to: urinary tract infections, pressure sores, autonomic dysreflexia, spasticity, contractures, depression, chronic pain, upper-extremity problems, bowel problems, deconditioning and weight gain, syringomyelia, sleep disorders, heterotopic ossification, renal disease/failure, poor cardiorespiratory function, and orthostatic hypotension (Graitcer & Maynard, 1991).

External Consumer Influence

Paralyzed Veterans of America (PVA) provides roughly $500,000 per year for training grants submitted to its Education and Training Foundation. The priorities for training grants are usually developed by the board of directors, most of whom have a spinal cord injury or dysfunction. This board also responds to the PVA membership, all of whom have some type of spinal cord injury or dysfunction. Thus, there is a strong consumer influence on the training priorities before they are ever released for grant competitions. In fact the ETF grant submission guidelines require that proposals submitted must involve people with disabilities as part of the grants and project planning process.

Team Composition

The team consisted of nine topic experts in the area of secondary conditions. Six researchers (four of whom have a physical disability), a focus group of consumers with disabilities who either had, or were at risk of having a secondary condition. Team members were chosen based on their ability and willingness to serve on this project.

Formulate the Research Question

For the purposes of this training, team members determined the specific training needs to help people with spinal cord injuries to prevent and manage secondary conditions. The team decided to develop resource materials -- written in terminology consumers could understand -- about preventing and managing specific secondary conditions.

Prioritize Concerns and Develop Goals

In 1992, the Research and Training Center on Independent Living received a grant from the Education and Training Foundation to develop and disseminate these materials. Development and prioritization of the materials was based on consultation with people at risk for secondary conditions to learn (a) which secondary conditions should be priorities; (b) what personal strategies consumers used to prevent or manage secondary conditions; and (c) which dissemination strategies should be used to target relevant audiences.

The first step was to convene a focus group of consumers who experienced a variety of motor-sensory disabilities and who were at risk for secondary conditions. This focus group invited consumers to share anecdotal information concerning frequency of secondary conditions and costs, both in terms of medical treatment and of time away from activities or isolation from society. This information helped the team shape a survey to gather data regarding the incidence and consequences of secondary conditions. The survey was randomly distributed nationally to over 400 consumers with physical disabilities. The survey results identified twelve secondary conditions of most concern to responders: (a) pressure sores, (b) urinary tract infections, (c) chronic pain, (d) chronic fatigue, (e) joint problems, (f) SCI and aging, (g) spasticity, (h) contractures, (i) deconditioning and (j) weight gain, (k) depression, (l) bowel dysfunction, and (m) sleep disturbance. Upon consultation with Hispanic PVA members, this last category was replaced with sexuality issues, due to the strong need for this information--and lack of it-- in their culture.

Shape Procedures and Methods

The team then devised a system to incorporate consumer input into every step of the production of a booklet on each of these secondary condition topics. The process began with a literature search of approximately 100 to 120 articles from medical, health, and psychological databases for information on the specific topic. This information was synthesized, developed into an outline, and then reviewed by the team for completeness and logic. From this outline, an editor wrote a 16-26 page manuscript summarizing the reviewed information in consumer-friendly language.

A consumer focus group consisting of nine consumers with varying physical disabilities reviewed the draft manuscript and provided feedback on accuracy, completeness, and readability. Focus group members also contributed information on lessons learned from their personal experiences with secondary conditions, and management techniques they developed. For example, one member noted that there was an increased risk of pressure sores for pregnant women with spinal cord injuries who used wheelchairs because of the extra weight added to their body frame. This helpful tip prompted researchers to highlight the need for frequent pressure relief exercises for pregnant women who are wheelchair users.

In addition to consumer focus groups, subject matter experts also reviewed the manuscripts. These were individuals with national reputations for expertise in their disciplines; many who were also people with disabilities, which provided an additional dimension of consumer input to the project.

Results

The results of this process were two-fold. First, a 2-page camera-ready newsletter insert with information about each specific secondary condition was produced. Many disability organizations communicate with their consumers via newsletter, therefore an insert on each topic was provided to each organization to complement the more detailed resource booklets. The newsletter inserts encouraged readers to contact the disseminating organization for further information about secondary conditions and provided an additional opportunity for consumer input. Each insert solicited personal tips from consumer readers to assist others on how to prevent or manage secondary conditions. Submitters were paid $40.00 for each tip used in later newsletter inserts. The second product was a resource booklet on each of the identified secondary condition topics. These resource booklets were intended to be used in the organizations' libraries for direct consumer use in centers for independent living, Paralyzed Veterans of America chapters, and National Spinal Cord Injury Association chapters.

Dissemination

The team targeted the above organizations as dissemination points of the developed materials. Additionally, these products were promoted in the Research and Training Center's material catalogs and Internet home page, and PVA's national magazine

Paraplegia News.

Through the multiplicative effect of newsletter distribution and through other distribution sources the potential readership for these materials was estimated to be approximately 400,000 to 500,000 readers per secondary condition topic. Initially, all publications were written in English. However, after reviewing the incidence and prevalence of injury among Hispanic people, and consulting with Hispanic PVA members, the CET approached PVA's Education and Training Foundation (ETF) to fund translation and publication of each the secondary condition resource booklets in Spanish. After receiving ETF approval and funding, the booklets were written in Spanish by professional translators, and disseminated to Hispanic/Latino consumers with disabilities in Texas, Florida, California, New York, New Mexico, Mexico, Puerto Rico, and Peru.

Consumer-Valued Outcomes

Consumers have increasingly recognized that good health and prevention of secondary conditions is an important part of living independently (White, Seekins, & Gutierrez, 1996). People with disabilities are more enthusiastic about taking personal control over their health than having medical professionals make decisions in "their best interest" (DeJong, 1979).

Social importance.

The incidence of secondary conditions for persons with disabilities is high. For the purposes of illustration we will use the secondary condition of pressure ulcers. Data show that at least 62.5% of spinal injured patients in the Model SCI System Centers have had at least one pressure ulcer (Yarkony & Heinemann, 1995). The development of pressure sores may result in time away from work, extended periods of isolation (White, Mathews, & Fawcett, 1989) and loss of independence (White, Seekins, & Gutierrez, 1996). Economically, the medical treatment for severe cases of pressure ulcers can cost as much as $90,000 per wound (Wharton, Milani, & Dean, 1987).

Ease of implementation.

The materials were developed to be integrated with naturally occurring practices at targeted dissemination sites. The majority of the sites had a newsletter they regularly published. The camera-ready inserts called "Second Thoughts" were developed to fit in with most organizations' newsletters. The accompanying resource booklets were designed to be incorporated into each organization's library to be used as a reference tool by both staff and consumers.

Quality of life.

As people with disabilities age they are more vulnerable to the interactive effects of aging and onset of secondary conditions (Whiteneck et al., 1993). Consumers can incorporate the information and suggested behaviors contained in these materials to help postpone premature onset of secondary conditions which occur with the aging process. A decrease in frequency, severity, and duration of secondary conditions will promote a higher quality of life for consumers.

Summary and Discussion

This paper discussed the role of consumers as collaborators in community based disability research and training. A comprehensive model of participatory action research was described with emphasis on four primary components: external consumer influence, involvement of the consumer empowered team, the research process, and consumer-valued outcomes. Illustrations of these components were provided by describing two research and training projects conducted by the Research and Training Center on Independent Living. These projects demonstrated how adherence to the model could be conducted in actual research and training settings. Additionally, these exemplars indicated how the team played a central role in shaping and amplifying the participatory action research process. The results from the identified research and training projects suggest that PAR helped produce outcomes which were valued by the consumers likely to benefit from the interventions.

Embracing the philosophy and practice of PAR is important for psychologists conducting research in the community. PAR enhances the trust relationship between the researchers and those being studied. Additionally, PAR allows consumer-collaborators a voice in the priorities of the research; of the goals, procedures, and outcomes of the research; and how the results are disseminated. As community psychologists collaborate with consumers on particular research issues they gain real-life insights on the person-context factors which may contribute to problems affecting people with disabilities.

While the PAR approach is increasingly discussed and used by researchers (Balcazar et al., 1998; Boyce, 1998; Campbell, Copeland, & Tate, 1998; and Krogh, 1998), it is not without concerns. For example, time needed to conduct research is increased as consumer-collaborators become involved. Collaboration also encourages researchers to develop research that is both rigorous and relevant. Sometimes this might mean justifying why they are choosing a specific research design or procedure to the team. Although it has been suggested that the PAR approach is more costly in terms of the increased numbers of individuals associated with a project, the argument could also be made that PAR is cost effective when it shapes research interventions that are then actually used by their intended targets rather than simply appearing as publications in professional journals.

The great English philosopher and logician Bertrand Russell said, "Although this may seem a paradox, all exact science is dominated by the idea of approximation." Perhaps if we, as community psychologists, make enough successive approximations of what PAR should be, it will contribute to a more robust science, a more relevant science, and certainly a more friendly, and empowering science.

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Figure 1.

An illustrative model of the Participatory Action Research process.

Author Note

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Concerns Report Method for Citizens with Disabilities

Overview and Brief History of the Citizens' Concerns Report Method for Citizens with Disabilities

The "Disabled Citizens' Concerns Report Method" was developed in 1980 by the Institute on Public Policy at the University of Kansas. The Independent Living Movement was less than a decade old; the first ten Centers for Independent Living had just received their start-up grants from RSA (Rehabilitation Services Administration), totaling $2 million for that year's entire national independent living budget. Citizens with disabilities had won their first big federal civil rights battle, with the sit-in in Sacramento, CA forcing Secretary Joseph Califano, of what was then HEW (Department of Health, Education and Welfare) to sign and publish the Section 504 Regulations, in 1976.

During the eighties, the Disabled Citizens Concerns Report Method was used to involve and organize people with disabilities around issues important to them in their local communities, and to provide them with a way to influence community leaders to improve conditions for people with disabilities, and to aid agencies'and service providers in planning programs that met community needs.

By the time the ADA was being debated in Congress in 1989, the Disabled Citizens Concerns Report Method had been used in over 30 applications, six of them statewide, including over 20,000 people with disabilities surveyed, by the Research and Training Center on Independent Living at the University of Kansas. The staff there organized and summarized the archived results and published them for use as testimony in support of the ADA, mailing the information to all Senators and Congressional Representatives.

The nineties brought an explosion of technology and communication that made the world a lot smaller for all of us, and forever changed the world for people with disabilities. An individual's community widened to include the state, nation, and even the whole planet. Anyone who could move a mouse or trackball, with hands or voice, became potentially employable. Access to transportation increased, and 'consumer control" became more than a buzzword, as it developed into a mandated element not only in independent living, but also in vocational rehabilitation. People with disabilities increasingly took control of their own lives and the programs designed to serve them, including control of one's own vocational rehabilitation plan and attendant services. Consumer controlled councils were formed, by federal requirement, at the state level. Rehabilitation services were overseen by a State Rehabilitation Council (SRC), the majority of whose members had to be people with disabilities or parents of children with disabilities, and that same representation was mandated for Statewide Independent Living Councils (SILCs).

Now, as we move into the next millennium, disability rights advocates are working, with some success, toward a national personal assistant services program, MICASSA, as well as Social Security and health care reform. The need is more critical than ever for a tool like the Concerns Report Method, to involve and empower people with disabilities to craft and to usher into law legislation to benefit them, to plan and control their own programs and services, and to assert themselves as citizens of their communities, states, and the nation.

In addition to meeting the general need by groups such as Centers for Independent Living – now numbering over 400 from the ten in 1980 – and other organizations of citizens with disabilities, the Concerns Report Method could satisfy the regulatory requirement of SRCs and SILCs to conduct periodic needs assessment and satisfaction surveys, and to hold public forums.

In keeping with the times, the "Disabled Citizens' Concerns Report Method" has changed its name to, "Concerns Report Method for Citizens with Disabilities,"and the CRM manual has been rewritten, not only to update terminology, but also to accommodate new methods, available through new technology, and innovative ideas used in more recent Concerns Report Method applications, to communicate, produce, distribute and collect the surveys; and to hold meetings, and to publish and distribute the final report. Also in keeping with the times, recognizing that state and federal legislation and programs have an increasing impact on the lives of people with disabilities, "community" is no longer assumed to be a town or neighborhood, or even a city or county, but as big as it needs to be for the issued involved.

The broad goal of the Concerns Report Method is to help citizens with disabilities to identify the perceived strengths and weaknesses in their community, to discuss specific options to build on strengths and solve problems, and to present this information to decision makers, advocates, and service providers.

The Concerns Report

Involving consumers in planning for rehabilitation and independent living services

American Rehabilitation, July-August-Sept 1988
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The Concerns Report:

Involving consumers in planning for rehabilitation and independent living services

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This article describes a process—the Concerns Report Method—for involving consumers in planning for rehabilitation and independent living services. Using consumer-generated surveys and town meetings, the method identifies community strengths, problems, and ideas for enhancing prospects for independent living. Developed at the University of Kansas Research and Training Center on Independent Living (RTC/IL), the Concerns Report Method can be used to help establish state independent living councils, develop local advocacy groups and improve state and local planning for rehabilitation and independent living.

Many aspects of communities have a profound impact on the success of rehabilitation services. Features such as inaccessible public transportation or unaffordable heath insurance may undermine efforts to assist people with physical disabilities in meeting their independent living goals. Discovery of each handicapping (or facilitating) features of communities is a critical step in planning for rehabilitation and independent living (IL) services.

The Concerns Report Method

To contribute to planning, the *Concerns Report Method* uses three features: a working group, a Concerns Survey, and a town meeting (Fawcett, Seekins, Whang, Muiu, & Suarez de Balcazar, 1982).

The working group consists of six to eight consumers with representative disabilities. Thee consumers develop a Concerns Survey, which forms the basis for the method. This they do by reviewing a comprehensive index or menu of several hundred items that covers 18 topic areas, including employment, health, transportation, and housing. The working group selects approximately 30 items of local concern to appear on the survey. Directors of centers for independent living (CILs), state directors of vocational rehabilitation (VR) and other administrators also may be sources of items.

Each survey item has two parts: How *important* is this issue? How *satisfied* are you with it? Below is an example of an item that was used in a survey developed with the Wyoming Division of Vocational Rehabilitation:

How important is it that…"	How satisfied are you that…"
Not Very	Not Very
0 1 2 3 4	0 1 2 3 4

"…health care insurance is affordable to you?

The survey also included demographic items of interest to planners such as the type of disability, employment status and level of household income.

The working group develops the survey, which is then administered to all citizens with disabilities in the community. Mailing lists for IL and VR clients, Social Security Disability Insurance, the state's department of motor vehicles, and other sources are used to distribute questionnaires by mail. Some groups have also used door-to-door canvassing, toll-free telephone numbers or receptionists at agencies to administer the surveys.

RTC/IL staff analyze the data and report the results to the sponsoring organization. Average scores for importance and satisfaction are used to identify relative strengths (i.e., items of high importance and high satisfaction) and possible problems (i.e., items of high importance and low satisfaction). Data analysis is provided for the entire survey, but additional analyses based on variables, such as geographical area or type of disability, can also be prepared.

The town meeting is a critical component of the *Concerns Report Method*. These well-publicized meetings are held in cities in which vocational rehabilitation offices or CILs are (or might someday be) located. They are usually led by consumers with support from staff of local sponsoring organizations. In the town meetings, people share their experiences on each issue, identify and discuss dimensions of the problems, brainstorm alternatives, and plan strategies to promote change. Participants see that their own experiences are not unique and that they can work together to solve common concerns.

The product of this process is as unique *Concerns Report*. Each report includes survey results, a transcript of ideas generated in the town meeting and an executive memo that summarizes the community's strengths and problems and ideas for improvement as identified by those who live in that community.

Most *Concerns Report* applications require 6-12 months to develop a mailing list, create a working group, distribute and collect surveys, conduct town meetings, and complete reports. Costs for data entry and analysis, technical assistance and other activities are assumed by the sponsoring organization. These costs are based on the number of consumers who complete the survey and time required by staff.

Development of the Concerns Report Method

The *Index of Concerns and Procedures* used in the *Concerns Report Method* is the product of years of development and refinement. To generate initial items for the index, we used a conceptual matrix that linked basic human values—safety/security, self-esteem, freedom, justice, and general welfare—to specific community functions such as transportation, housing, employment, and commercial services. For example, the specific index item, "City streets and sidewalks provide safe and easy access to you," reflects a value for community safety and the function of transportation. Several hundred initial items were developed in this way.

This list was extended by reviewing the literature on independent living and rehabilitation and analyzing existing handicapping conditions in communities. Additional items were added based on structured interviews with citizens with disabilities, administrators, service providers, and researchers working in the field of independent living and rehabilitation. These participants provided feedback on the wording of existing items and contributed new items based on their experience. Multiple applications of the *Concerns Report* have resulted in many additional items and several revisions of the original index.

Evaluation and Dissemination of the Concerns Report Method

Research in two early applications examined the validity and reliability of the *Concerns Report Method*. Overall high ratings of helpfulness, completeness and representativeness of the index and usefulness of the survey suggest that these surveys adequately sampled the concerns of citizens with disabilities. High levels of satisfaction of working group members and participants in town meetings were also noted in both communities.

Finally, measures of test-retest reliability were obtained in two separate early applications to assess whether the *Concerns Report* produced similar results on repeated measurements. The *Concerns Report* produced highly consistent sets of data, with approximately 90 percent of the importance ratings and 80 percent of the satisfaction ratings varying by 1 rating point or less. Taken together, these measures suggest that the *Concerns Report* is a valid and reliable method for assessing concerns.

Technical assistance is available through the University of Kansas RTC/IL to organizations who wish to conduct a *Concerns Report* application. We provide instruction on how to obtain mailing lists, put together a working group, develop a concerns survey, distribute questionnaires, conduct a public meeting, and prepare a final report of identified concerns and suggestions for improvement.

To date, the method has been used in over 322 counties in 10 states and has involved about 15,000 consumers in the United States. Statewide applications for vocational rehabilitation agencies and state planning councils have been conducted in Indiana, Kansas, North Dakota, Oklahoma, and Wyoming. CILs have sponsored applications in 13 sites ranging in size from rural Viburnum, Missouri to Los Angeles, California.

Implications for Independent Living and Rehabilitation

Setting the local agenda for improvements is probably the most significant use of *Concerns Report* information. For example, a CIL in Los Angeles used the concerns report data, which identified specific problems in housing and transportation, to set major goals for its long-range plan. A *Concerns Report* provides a focus for constructive improvements in the agencies and broader social and physical environments in which consumers attempt to live independently.

Information about strengths and problems can also be used to justify maintenance or expansion of human services. For example, *Concerns Report* information was used in Lawrence, KS to successfully justify a request for Community Development Block Grant funds to purchase a new lift van for a CIL. Similarly, statewide applications of the *Concerns Report* might help demonstrate state needs in a particular area that could best be met by expanding VR services or establishing an IL program.

The *Concerns Report* is a tool state VR agencies can use to satisfy federal requirements for policy development in VR and IL programs. The *Concerns Report* could be used to provide consumer-generated information and views on VR and IL service and program needs.

Federal regulations require state VR agencies to seek opinions of current and former recipients of VR services in developing policy, planning programs, forming legislative and budget proposals, and other such activities. There are several requirements in Title VII of the Rehabilitation Act, as amended, that include consumer involvement. IL regulations and IL state plans also call for consumer involvement in developing and revising state plans. In addition, IL regulations call for providing technical assistance to urban and rural poverty areas that provide IL and VR services.

The *Concerns Report Method* provides a technique for identifying and organizing consumers and producing valid information on consumers' needs to providers of IL services. It offers an efficient way of generating constructive consumer involvement in planning for IL services.

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Community Concerns Report Participation Survey

Key Informants Meeting for the Community Concerns Report Participation Survey

From June 1-3, 2001 the RTC/FPIL hosted a meeting of thirteen Key Informants from all over the US to discuss and develop a Community Concerns Report survey, to identify the needs of Americans with varying disabilities, chronic conditions, and cultural backgrounds. The two-day meeting allowed extensive discussion about critical issues facing the disability community that should be included in the survey, as well as recommendations for survey dissemination. This group formed the "working group" of the CRM process, and actually selected items that would be included in the survey on Full Participation. The group included members representing "emerging" disability groups, or disability groups who often do not use the services of Centers for Independent Living.

One of the most challenging issues for this working group was deciding how to craft questions that would solicit responses both from persons who consider themselves to be "persons with disabilities" and from those with chronic health conditions, who do not necessarily consider themselves disabled, but who could benefit significantly from independent living philosophy and services. This dichotomy raised lots of discussion points, ranging from "What's wrong with disability pride?" to "If we frame the questions to address the concerns of people with disabilities only, then how will we solicit responses from people who have chronic conditions, but do not consider themselves disabled--will they understand that the survey is aimed toward them?"

Key Informants Participating in the Working Group:

Michael Blatchford (AZ)

Mike Gomez (ND)

Linda Gonzales (OH)

Anne-Marie Hughey (DC)

Leonard Jason (IL)

Barbara Knowlen (NY)

Mary Lamielle (NJ)

Mark Obatake (HI)

Mike Oxford (KS)

Lee Schulz (WI)

Liz Sherwin (IL)

Courtland Townes, III (MA)

Sherry Watson (NM)

Outcome: This working group created a draft survey which was finalized, piloted, and converted into online, email and paper versions. The survey was piloted for both format and content with people with disabilities before dissemination. The survey was disseminated through CILs, disability-related organizations, chronic health condition support organizations, and related list serves and web sites during 2002.

Full Participation in Independent Living Concerns
[As presented on http://www.rtcfpil.org/survey.htm]

Dear Participant:

We are writing to ask you to answer the following questions on full participation in independent living.

As a person with a disability or chronic health condition, YOU are an expert regarding your experiences in community participation. We are seeking information about your day-to-day experiences, and about how well you are able to participate as a full member of your community. Your feedback about barriers and facilitators to independent living is extremely important to us. We assure you that all of the information you provide will be kept fully confidential, and that any reports developed from this project will not identify you as an individual in any way.

This survey has been thoughtfully developed with the assistance of leaders in independent living, advocacy, and self-help organizations from all over the country. Some of the creators of this survey are listed below.

So what are you going to get out of this? If you answer the questions and send the forms back to us, you will provide important information that can help to influence programs and services for individuals like yourselves in the future.

If you enter your name and address in the space provided, we will also send you an advocacy tool -- a newly revised copy of our brochure, Guidelines for Reporting and Writing About People with Disabilities.

Thank you in advance for taking the time to respond and to assist us in this project.

Glen White, Director RTCFPIL
Mike Oxford, President NCIL
Mike Schafer, President APRIL

Definitions of Terms

Centers for Independent Living: A Center for Independent Living (CIL) is a resource organization that is run by a majority of people who have disabilities, and serves people with all types of disabilities. CILs are community agencies (not residences) that provide four core services: advocacy, information and referral, peer counseling, and independent living skills training.

People with disabilities/chronic health conditions: People who have some type of difference or functional limitation or health problem, that creates the need for accommodation to participate in the community. The person might also be protected under one or more civil rights laws, such as the Americans with Disabilities Act (ADA).

Access: The usability of an environment, system, or device for a person with a disability or chronic health condition. Access in the context of disability or chronic health conditions means no or minimal barriers. Examples of access include a captioned TV program, a ramped store entrance, a fragrance-free building, or a large-print or brailled publication.

Assistive technology: An item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of an individual with a disability (Brandt & Pope, 1997, p. 150). Some examples of assistive technology are hearing aids, wheelchairs, air filtration devices, and brailling devices. Assistive technology can be as simple as a fork with a large handle that is easy to grip, or as complex as an electronic system that allows a person who cannot use his arms to open doors and turn on the television.

Instructions

Eligibility: You are eligible to participate in this survey if you are a person with a disability or a chronic health condition. Please use whatever help you may need, such as someone writing out your answers, to respond to the questions. However, it is your answers, based on your experiences as a person with a disability or chronic health condition, that we want.

Consent: If you answer the questions and send the survey back to us, we will assume that you are giving us consent to use the information that you give us. We will not use your name or other personal information in any way, and your answers will be used only in a group with answers from other people.

For Part 1:

We are asking you to rank the importance to you and your satisfaction for 48 issues. The questions are on a single line and the choices are on individual lines following the question. For example, you will be asked to mark importance on a scale of not important, somewhat important, neutral, moderately important and very important. The format is the choice option, for example somewhat important, a blank, and a dash or minus sign. Please type an X after the dash on the choice that best describes your feelings. Not applicable is always the first choice. Part 2 requests demographic information. Most questions are formatted in the same way as in Part 1, but some ask you to type in information such as the year of your birth.

Full Participation in Independent Living Concerns (Part 1).

Please read the following questions and place an X behind the option that best expresses your feelings.

1. How important is it that you make your own personal decisions about your life?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

2. How satisfied are you that you make your own personal decisions about your life?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

3. How important is it that you set and pursue your own personal goals with or without help?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

4. How satisfied are you that you set and pursue your own personal goals with or without help?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

5. How important is it that you speak up for what you need and want?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

6. How satisfied are you that you speak up for what you need and want?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

7. How important is it that you work with others for the rights of people with all types of disabilities/chronic health conditions?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

8. How satisfied are you that you work with others for the rights of people with all types of disabilities/chronic health conditions?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

9. How important is it that you as a person with a disability/chronic health condition are treated as an equal citizen?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

10. How satisfied are you that you as a person with a disability/chronic health condition are treated as an equal citizen?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

11. How important is it that you as a person with a disability/chronic health condition can fully participate in society?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

12. How satisfied are you that you as a person with a disability/chronic health condition can fully participate in society?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

13. How important is it that you are generally safe from harm (physical, emotional, and environmental) in your community?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

14. How satisfied are you that you are generally safe from harm (physical, emotional, and environmental) in your community?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

15. How important is it that you have equal access to emergency notification in your community?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

16. How satisfied are you that you have equal access to emergency notification in your community?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

17. How important is it that you are treated fairly and respectfully by the courts, police and other public officials?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

18. How satisfied are you that you are treated fairly and respectfully by the courts, police and other public officials?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

19. How important is it that housing that meets your needs is accessible and affordable for you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

20. How satisfied are you that housing that meets your needs is accessible and affordable for you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

21. How important is it that health care providers of all types are sensitive to your health care needs?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

22. How satisfied are you that health care providers of all types are sensitive to your health care needs?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

23. How important is it that comprehensive health care is available to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

24. How satisfied are you that comprehensive health care is available to you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

25. How important is it that comprehensive health care is affordable for you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

26. How satisfied are you that comprehensive health care is affordable for you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

27. How important is it that comprehensive health care is accessible to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

28. How satisfied are you that comprehensive health care is accessible to you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

29. How important is it that you receive adequate legal information from agencies in your community?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

30. How satisfied are you that you receive adequate legal information from agencies in your community?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

31. How important is it that you have a role in the decision-making and policy processes regarding services that affect you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

32. How satisfied are you that you have a role in the decision-making and policy processes regarding services that affect you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

33. How important is it that community service providers' programs and services are barrier-free for you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

34. How satisfied are you that community service providers' programs and services are barrier-free for you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

35. How important is it that community service providers are sensitive to your needs?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

36. How satisfied are you that community service providers are sensitive to your needs?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

37. How important is it that transportation that meets your requirements is affordable?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

38. How satisfied are you that transportation that meets your requirements is affordable?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

39. How important is it that transportation that meets your requirements is accessible?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

40. How satisfied are you that transportation that meets your requirements is accessible?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -

Moderately satisfied -
Very satisfied -

41. How important is it that local businesses, including stores, restaurants, and vendors of services are accessible to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

42. How satisfied are you that local businesses, including stores, restaurants, and vendors of services are accessible to you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

43. How important is it that local businesses provide the services you need?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

44. How satisfied are you that local businesses provide the services you need?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

45. How important is it that your place of worship and its programs are barrier-free?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

46. How satisfied are you that your place of worship and its programs are barrier-free?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

47. How important is it that your place of worship and its programs allow you to participate to the extent that you choose?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

48. How satisfied are you that your place of worship and its programs allow you to participate to the extent that you choose?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

49. How important is it that you and your family are accepted as members of the community?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

50. How satisfied are you that you and your family are accepted as members of the community?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

51. How important is it that your rights as a parent are respected?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

52. How satisfied are you that your rights as a parent are respected?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

53. How important is it that the media identifies issues affecting you in a fair and accurate manner?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

54. How satisfied are you that the media identifies issues affecting you in a fair and accurate manner?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

55. How important is it that you can access information and entertainment from the media (e.g., TV, radio, news, internet, etc.)?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

56. How satisfied are you that you can access information and entertainment from the media (e.g., TV, radio, news, internet, etc.)?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

57. How important is it that you receive the types and amounts of personal assistance services you need?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

59. How satisfied are you that you receive the types and amounts of personal assistance services you need?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

60. How important is it that you have the option to manage (e.g., hire, train, schedule, fire) your personal assistants?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

61. How satisfied are you that you have the option to manage (e.g., hire, train, schedule, fire) your personal assistants?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

62. How important is it that recreation sites and programs are accessible to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

63. How satisfied are you that recreation sites and programs are accessible to you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

64. How important is it that recreation sites and programs meet your needs?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

65. How satisfied are you that recreation sites and programs meet your needs?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

66. How important is it that voter registration is accessible for you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -

Very important -

67. How satisfied are you that voter registration is accessible for you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

68. How important is it that polling places in your community are accessible?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

69. How satisfied are you that polling places in your community are accessible?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

70. How important is it that affordable coverage for the purchase of assistive technology is available to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

71. How satisfied are you that affordable coverage for the purchase of assistive technology is available to you?

Not applicable -
Very dissatisfied -

Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

72. How important is it that the policies and practices related to purchase, repair, and replacement of assistive devices are reasonable and allow for timely access to equipment?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

73. How satisfied are you that the policies and practices related to purchase, repair, and replacement of assistive devices are reasonable and allow for timely access to equipment?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

74. How important is it that a variety of assistive devices are available for your trial before purchase?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

75. How satisfied are you that a variety of assistive devices are available for your trial before purchase?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -

Very satisfied -

76. How important is it that competent and respectful peer counseling is available to you?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

77. How satisfied are you that competent and respectful peer counseling is available to you?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

78. How important is it that you have access to fully-integrated, quality educational programs and facilities in your community?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

79. How satisfied are you that you have access to fully-integrated, quality educational programs and facilities in your community?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

80. How important is it that you have the necessary accommodations to succeed in your educational program?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

81. How satisfied are you that you have the necessary accommodations to succeed in your educational program?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

82. How important is it that programs are available and adequate to assist you in your transition to employment and community living?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

83. How satisfied are you that programs are available and adequate to assist you in your transition to employment and community living?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

84. How important is it that you have the service and support you need to obtain and succeed in employment?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

85. How satisfied are you that you have the service and support you need to obtain and succeed in employment?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

86. How important is it that you are given the same opportunities as non-disabled job applicants?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

87. How satisfied are you that you are given the same opportunities as non-disabled job applicants?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

88. How important is it that you have the same chances for advancement and promotion as non-disabled employees?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

89. How satisfied are you that you have the same chances for advancement and promotion as non-disabled employees?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

90. How important is it that you can earn enough in salary and benefits in your employment to meet your living needs?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

91. How satisfied are you that you can earn enough in salary and benefits in your employment to meet your living needs?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

92. How important is it that the service you receive (or have received) from the state vocational rehabilitation agency help you get the job or training that you wanted?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

93. How satisfied are you that the service you receive (or have received) from the state vocational rehabilitation agency help you get the job or training that you wanted?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

94. How important is it that vocational rehabilitation counselors are supportive of your self-employment goals?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

95. How satisfied are you that vocational rehabilitation counselors are supportive of your self-employment goals?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

96. How important is it that the services you receive (or have received) from a Center for Independent Living help you to live more independently?

Not applicable -
Not important -
Somewhat important -
Neutral -
Moderately important -
Very important -

97. How satisfied are you that the services you receive (or have received) from a Center for Independent Living help you to live more independently?

Not applicable -
Very dissatisfied -
Somewhat dissatisfied -
Neither -
Moderately satisfied -
Very satisfied -

Demographic Information (Part 2).

1. What year were you born?

(year) -

2. What is your sex?

Male -
Female -

3.a. What is your current marital status?

Divorced -
Married -
Separated -
Single -
Widowed -

3.b. While the following question may seem personal, we ask it to learn how personal choices might be limited due to the need to qualify for benefits. Have you ever had to limit your choice regarding marriage as a person with a disability or chronic condition because of legal or financial consequences?

Yes -
No -
Prefer not to answer -
Not applicable -

4. Are you Spanish/Hispanic/Latino?

Yes -
No -

5. What do you consider your race? (Please choose all that apply.)

American Indian or Alaskan Native -
Asian or Pacific Islander -
Black or African American -
White -
Other __________ -

6. What is the highest level of education that you have completed?

No formal schooling -
Formal schooling but no high school diploma or GED -
High School graduate (diploma or GED) -
Post-secondary vocational/technical school -
Some college or post-high school, but no degree -
Associate degree (AA, AS, etc.) -
Bachelor's degree (BA, BS, etc.) -
Graduate Degree -

7a. What is your employment status? (Please choose all that apply.)

Homemaker -
Not Working -
Retired -
Self-employed -
Student -
Volunteer -
Work full time for pay in the community -
Work full time for pay out of my home -

Work part time for pay in the community -
Work part time for pay out of my home -

7b. Do you earn at least minimum wage of $5.15 per hour?

Yes -
No -
Not applicable -

8. Do you receive income, benefits, or assistance from any of the following programs or services? (Please choose all that apply.)

Any public assistance or welfare payments from the state or local welfare office -

Child care subsidy -
Federal Government and Retirement Annuity -
Food stamps or WIC -
Personal Assistance Services (PAS) with public funding -

Section 8 or other housing assistance -
Social Security Disability Income (SSDI) -
Social Security or Railroad Retirement -
Supplemental Security Income (SSI) -

Unemployment benefits -
Veterans' Administration payments -
Workers' Compensation -
Other -

If other, please enter -

9. Where do you live most of the time?

Car or truck, tent, porch, outdoors, or similar situation -

Developmental center/institution -
Dormitory -
Group home -
Halfway house, safe house, or homeless shelter -
Housing cooperative -
Nursing home -
Own house, apartment, condominium, or mobile home -
Parents' or other relative's home -
Rooming house -

Other -

10a. How many other people (children or adults) live or stay with you now? Please list a number for each.

Adults related to you -
Adults unrelated to you -
Children -

10b. How many of the people listed above provide personal assistance or homemaking services to you?

With pay -
Without pay -

11. What disabilities or chronic conditions do you experience? (Please choose all that apply.)

1. Amputation -
2. Arthritis/auto-immune disorders -
3. Asthma -
4. Brain injury (TBI) -
5. Blindness/visual impairment -
6. Breathing problems or lung disease -
7. Cancer -
8. Cerebral palsy -
9. Chronic fatigue syndrome -
10. Chronic pain -
11. Deaf/hearing impairment -
12. Depression -
13. Diabetes -
14. Heart disease -
15. Infectious disease (HIV, hepatitis, tuberculosis) -
16. Kidney/renal disease -
17. Learning disability -
18. Mental retardation -
19. Multiple chemical/electrical sensitivities/environmental illness -
20. Multiple sclerosis -
21. Muscular dystrophy -
22. Orthopedic impairment -
23. Post-polio syndrome -
24. Psychiatric survivor/mental illness -
25. Seizure disorder/epilepsy -
26. Stomach/digestive disorders -

27. Spina bifida -
28. Spinal cord injury -
29. Stroke -

30. Other (Describe briefly) -

____
____
____

12. If you have a primary disability or chronic health condition, or one that seems more serious than others or that presents the most significant barrier to full participation in your desired community activities, please enter a mark beside that one condition in the list below.

1. Amputation -
2. Arthritis/auto-immune disorders -
3. Asthma -
4. Brain injury (TBI) -
5. Blindness/visual impairment -
6. Breathing problems or lung disease -
7. Cancer -
8. Cerebral palsy -
9. Chronic fatigue syndrome -
10. Chronic pain -
11. Deaf/hearing impairment -
12. Depression -
13. Diabetes -
14. Heart disease -
15. Infectious disease (HIV, hepatitis, tuberculosis) -
16. Kidney/renal disease -
17. Learning disability -
18. Mental retardation -
19. Multiple chemical/electrical sensitivities/environmental illness -
20. Multiple sclerosis -
21. Muscular dystrophy -
22. Orthopedic impairment -
23. Post-polio syndrome -
24. Psychiatric survivor/mental illness -
25. Seizure disorder/epilepsy -
26. Stomach/digestive disorders -
27. Spina bifida -
28. Spinal cord injury -
29. Stroke -

13. How many years have you been disabled or had a chronic health condition?

Enter number of years -

14. Because of a physical, mental, or emotional condition lasting 6 months or more, do you have any difficulty in doing any of the following activities? (Please choose all that apply.)

Learning, remembering, or concentrating -
Dressing, bathing, or getting around inside the home -
Going outside the home alone to shop or visit a doctor's office or engage in other activities -

Working at a job or business, or volunteering -

15. What county and state do you live in?

Name of County -
Name of State -

16. What is your zip code?

Zip code -

17. Have you ever used the services of a Center for Independent Living (CIL)? Refer to definition at top of survey, if needed.

Yes -
No -
Don't Know -

18. What is your individual (not household) MONTHLY income, including wages and/or cash benefits before taxes, if any?

Less than $550
$551 - $1,000 -
$1,001 - $1,499 -
$1,500 - $2,499 -
$2,500 - $3,999 -
$4,000 or more -

Optional Information (Part III).

Thank you for completing this survey. To thank you, we would like to provide you with a copy of an advocacy tool that we have developed. If you are interested in receiving this, please fill in the following information. To protect your confidentiality, we will destroy the information after we send you the item.

19.

Full Name -
Address 1 -
Address 2 -
City -
State -
Zip Code -

IL NET Presents

Teleconference: Full Participation in Independent Living: What Does it Mean?

September 25, 2002

Participants List

Illinois

Options CIL
22 Heritage Drive
Suite 107
Bourbonnais, IL 60914
Site Coordinator: Diane Schikora
Number of Participants: 8
Voice: 815-936-0100
TTY: 815-936-0132
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options@daily-journal.com

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TTY: 765-741-8332
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Maryland

Maryland
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Jefferson, MD 21755
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jameygeorge@prodigy.net

Michigan

Superior Alliance for Independent Living
129 West Baraga Ave.
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Marquette, MI 49855
Site Coordinator: Patricia Tonge
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New Jersey

DIAL, Inc. CIL
66 Mt. Prospect Avenue
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Clifton, NJ 07013
Site Coordinator: John Petix
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TTY: 973-470-2521
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New York

Long Island CIL
3601 Hempstead Turnpike
#208
Levittown, NY 11756
Site Coordinator: Tanny Deza-Ruzan
Number of Participants: 6
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IL NET Presents

Teleconference:

Full Participation in Independent Living: What Does it Mean?

September 25, 2002
Participants List

New York

S.I. Center for Independent Living, Inc.
470 Castleton Avenue
Stanton Island, NY 10301
Site Coordinator: Dorothy Doran
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New York

Northern Regional CIL
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Pennsylvania

Community Resources for Independence
222 Filmore Avenue
Erie, PA 16506-2944
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Ohio

The Ability Center
516 Perry Street
Defiance, OH 43512
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Pennsylvania

Liberty Resources Inc.
1341 North Delaware Avenue
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IL NET Presents

Teleconference:

Full Participation in Independent Living: What Does it Mean?

September 25, 2002
Participants List

Tennessee

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Virginia

Junction Center for Independent Living, Inc.
548 Park Avenue NW
Norton, VA 24273
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Fax: 540-679-5988
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Wisconsin

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600 W. Virginia Street
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Milwaukee, WI 53204
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FULL PARTICIPATION IN INDEPENDENT LIVING: WHAT DOES IT MEAN?

September 25, 2002

Teleconference Evaluation Form

WE VALUE YOUR OPINION! We review every evaluation form. Please give us your feedback about today's program by completing this form and mailing it back to: National Council on Independent Living; Attn: Toony Buppapong; 1916 Wilson Blvd., Ste. 209; Arlington, VA 22201.

	Not at all		Average		Excellent
Was the teleconference content:					
Organized?	1	2	3	4	5
Interesting?	1	2	3	4	5
Useful?	1	2	3	4	5
What you hoped it would be?	1	2	3	4	5
Overall content rating	1	2	3	4	5
How well did the trainers know the subject?					
Dot Nary	1	2	3	4	5
Glen White	1	2	3	4	5
How well did the trainers hold your attention?					
Dot Nary	1	2	3	4	5
Glen White	1	2	3	4	5

How relevant were the trainers' examples?					
Dot Nary	1	2	3	4	5
Glen White	1	2	3	4	5
Please rate the following overall:	**Poor**		**Average**		**Excellent**
Overall rating – Dot Nary	1	2	3	4	5
Overall rating – Glen White	1	2	3	4	5
Overall conference rating	1	2	3	4	5
	Low				**High**
How likely is it that you will use what you learned at this training?	1	2	3	4	5

How well did this training develop your skills and knowledge for...

	Low				**High**
1. designing and using consumer-oriented data collection?	1	2	3	4	5
2. understanding some of the unmet and emerging needs of people with disabilities?	1	2	3	4	5
3. how you and your consumers can participate in giving feedback on the survey results?	1	2	3	4	5
4. the implications of the survey results and how you can participate in problem solving about needs identified?	1	2	3	4	5

Please list 2 or 3 of the most important things you learned from this training.

What else do you wish you would have learned at this training?

What do you wish the training had spent more time on?

What do you wish the training had spent less time on?

What might prevent you from using the information on the job?

What would you like to see IL NET do as an on-site training?

What would you like to see IL NET do as a teleconference?

We appreciate any comments you can make that will help us do a better job:

THANK YOU FOR THE GIFT OF YOUR TIME

IL NET TRAINING PROJECT

Teleconference:
Full Participation in Independent Living: What Does it Mean?

Site Evaluation Form

On a scale from 1 (the lowest rating) to 4 (the highest rating), please rate your Site.

1. Did the Site Coordinator prepare the manual in the format that is accessible for you?

   Yes No N/A

   Comment:

2. Were you given page numbers in your format to correspond with regular print?

   Yes No N/A

   Comment:

3. Did you receive the training manual prior to the teleconference?

   Yes No N/A

   Comment:

4. Were you asked to participate in the Pre-Conference?

Yes No N/A

Comment:

5. How useful was the Pre-Conference?

1 (Low) 2 3 4 (High)

6. Were you asked to participate in the Post-Conference?

Yes No N/A

Comment:

7. How useful was the Post-Conference?

1 (Low) 2 3 4 (High)

8. Were you provided with a participants list and evaluation in a format accessible to you?

Yes No N/A

Comment:

9. Did the phone used for the teleconference have a clear connection?

Yes No N/A

Comment:

10. Did your Site Coordinator, make the teleconference accessible for

you, i.e. real time captioning, interpreters, assistive listening device etc.,?

Yes No N/A

Comment:

11. What would you like to see as in-service provided by your Site?

Site Coordinators this evaluation is for your records to enhance your sites learning experience.

Please return all forms to your Site Coordinator.

IL NET Presents

Full Participation in Independent Living: What Does it Mean?

September 25, 2002

Do-It-Yourself Kit

A Do-It-Yourself Kit of the **IL NET** National Teleconference is available. If you would like a Kit, please fill out the order form below.

Please Print or Type

Name: ____________________

Center: ____________________

Address: ____________________

Telephone: __________ Fax: __________

Number of sets: _____ x $125.00 = $__________
(shipping included)

Payment Information:

Credit Card#____________________**Exp.**__________

Print Name:____________________

Authorizing Signature:____________________
(By signing you authorize NCIL to charge the Kit to your credit card) Visa and MasterCard only.

Please mail order form and payment to :
National Council on Independent Living
1916 Wilson Blvd., Suite 209
Arlington, VA 22201
Attention: Toony Buppapong

IL NET Presents

Full Participation in Independent Living: What Does it Mean?

September 25, 2002

Audio Tape Order Form

An audio cassette of the **IL NET** National Teleconference training is available. If you would like a copy, please fill out the order form below.

Please Print or Type

Name: ______________________________

Center: ______________________________

Address: ____________________________

Telephone: ________________ Fax: ______________

Number of sets: _____ x $25.00 = $__________
(shipping included)

Payment Information:

Credit Card#________________________________**Exp.**______________

Print Name:____

Authorizing Signature:______________________________________
(By signing you authorize NCIL to charge the Audio Tape to your credit card) Visa and MasterCard only.

Please mail order form and payment to :
National Council on Independent Living
1916 Wilson Blvd., Suite 209
Arlington, VA 22201
Attention: Toony Buppapong